Autism Spectrum Disorders (ASD) Task Force Meeting Minutes

February 12, 2018

Taskforce members present: Gerry Teevens, Teresa Larsen, Kodi Pinks, Vicki Peterson, Jennifer Flores, Connie Lillejord

Taskforce members present-via polycom/phone: Maggie Anderson, Senator Joan Heckaman, John Watkins, Mary Anne Jaeger, Carol Johnson, Tom Carver, and Nancy Ulrich-Crotty

Absent: Tom Gaffaney

There is a quorum of taskforce members to vote

Guests (present and via polycom/phone): Katherine Barchenger, Kaitlin Kurtz, Melanie Phillips, Krista Fremming, Susan Gerenz, Loren Poppe, Paula Hinton, Trisha Page, Barb Stanton, Dr. Renee Boomgaarden, Janeen Nichols, Mark Beshad and Kaylee Schwab (KX news)

Meeting was called to order.

Review of minutes- November 2017 minutes were reviewed.

Teresa Larsen made the motion to approve; Vicki Peterson seconded. 13 yay/0 nay: motion passed.

2015-2017 budget status report; 2017-2019 enrollment/expenditures dashboard – by Katherine Barchenger (refer to attached charts)

- 2017 The average voucher amount spent was \$4,398/child per year.
 - Discussion:
 - Parental choice of purchases is the main reason for not spending the full \$12,500.
 - When the families identify a need for respite or tutoring, the full amount is usually spent. When the families use the voucher for sensory items, the full amount allocated for the child is usually not spent.
 - Families are encouraged to call the Autism Unit to assist them.
- In December, the waiver increased to 96 slots; this was an increase of 49 slots. Eight of these slots have been successfully filled.
- Letters have been sent to families on the waitlist and a follow-up phone call to each family was completed.
- It was estimated there are 86 children on the waitlist for the waiver. Children are being moved to waiver slots as quickly as possible, but it is a slow process due to new eligibility criteria (removal of the multidisciplinary team; need to submit diagnosis documentation and achieve a minimum score on the Vineland assessment).

Dr. Renee Boomgaarden from the ND Board of Psychological Examiners

- To license an applied behavior analyst (ABA), the person needs to have a doctorate or a master's
 degree from a program accredited by the Association for Behavior Analysis, pass a boardcertified behavior analysis (BCBA) exam, be certified by the behavior analysis certification board
 (if outside of ND) and pass the ND oral exam.
- To register an ABA: a bachelor's degree with certain educational qualifications, needs to be supervised by a licensed applied behavior analyst or a licensed psychologist and pass the ND oral examination.
- The board office recently changed locations. It was previously in Georgia and now it is in Bismarck. This could have caused some of the delays that were happening with licensing and registering.
- The board tries to schedule oral exams often as they can, but they meet a minimum of twice a
 year.
- The board issued temporary licenses to give applicants time to get all the needed paperwork together.
- The board is seeing an increase in people applying to become BCBAs.
- There are 21 licensed ABAs and two Registered ABAs.

Task Force Membership

- Welcome new members Jennifer Flores (self-advocate) and Catherine Yeager (psychologist) to the autism Task Force.
- There are two positions that need to be filled.
 - A licensed teacher with expertise in the area of autism spectrum disorder and a representative who is an enrolled member of a federally recognized Indian tribe.
 - Currently, there are three applications for the two positions; one qualifies for both positions.
- Task force members discussed the process that has been used in the past to review new
 member applications. Moving forward, the Department of Human Services will review the
 applications and make recommendations to the Governor.

Determine Face-to-Face meeting date for 2018

- Discussion held on if members were interested in a face-to-face meeting. It was pointed out this
 is not a requirement of the task force. If people can't travel, the option to connect remotely will
 still be an option.
- The May 14, 2018 meeting will be a face-to-face meeting.

ASD Task Force State Plan

ASD Task Force State plan workgroup

- The state plan work group asked the children and adult workgroups to populate the state plan
 template that speaks to the goals, objectives and action plan. The children and adult
 workgroups should also provide updates on progress they have made in identifying funding
 sources for activities.
- DHS designee will pull the ideas from each group into one document to be reviewed by the task force at the May meeting.
- During the time between the February meeting and the meeting in May, the workgroups need
 to look at the state plan, create objectives, timelines and who is responsible for those timelines
 and submit back to Melanie. The documents need to be to Melanie by Friday, April 13.
- Jennifer Flores joined the Adults workgroup.

Children's Workgroup

- Members of the children's workgroup: Gerry Teevens, Dr. Carver, Connie Lillejord, Susan Gerenz, Kodi Pinks, Kathy Barchenger, Carol Johnson, Stephen Olson and Lorena Poppe.
- Physician survey will be sent to the ND chapter of the American Academy of Pediatrics.
 - Dr. Carver is also planning to send to nurse practitioners (pediatrics) and family medicine providers.
- Discussion around handout 'Priority Recommendations for 2018'.

Adult's Workgroup

- Members of the adult's workgroup: Vicki Peterson, Teresa Larsen, Gerry Teevens, Kodi Pinks, Nancy Ulrich-Crotty, John Watkins, Krista Fremming and Barb Burghardt.
 - Vicki will add Jennifer Flores to this group.
- The group gathered information from various service providers that serve adults with autism. Please refer to the handout 'Adults with Autism'.
- The adult group also looked at national numbers for autism and they discussed the handout 'Adults with ASD'.
- Kodi Pinks stated that 538 people have been reported to the database and there are not many adults.
 - The Health Department is working with the ND Health Information Network (NDHIN) to see if they can flag autism diagnoses with ICD 10 codes, extract the information and send it to the Department of Health.

Survey that was completed in 2010 and 2014-Do we need a survey in 2018?

- In 2010 and 2014, DHS contracted with ND Center for Persons with Disabilities to administer a survey regarding services and gaps in North Dakota.
- The questions were the same on both surveys, so the results could be compared.

- In 2010, 187 people responded and in 2014, 110 people responded.
- All the questions related to autism. The topics of questions were: training, information/awareness, services, supports/resources and service coordination.
- The 2010/2014 survey results will be sent to the task force for review and continued discussion at the May meeting.

Out of home placement

- Discussion over concerns for younger children with an autism diagnosis and their families having to look at out of state placement.
- Resources are needed families struggling to find facilities that will take children that are younger and exhibiting strong behaviors.
- The point was made that this topic has come up in other setting i.e.: Medicaid Medical Advisory Committee.
- Maggie proposed to have a separate meeting on this topic with all concerned groups and will
 update the task force on the results of that meeting.

Strategies for working with schools to prevent suspensions, etc.

- DPI recognizes that training is essential for educators.
 - Every Student Succeeds Act (ESSA) is the new Federal Elementary/Secondary Act replaces 'No Child Left Behind'.
 - Teachers need training on how to write social-emotional goals.
 - DPI held a summer institute for training for new special education teachers. They realize
 the need for the teachers that have been teaching for awhile to be trained and that they
 want to be trained, so they are holding another training.
 - Special Education Directors Leadership Institute is another training resource.
- Families need support when they are going through the IEP process. Coaching for parents and professionals is a need and would be a great tool.
- Service managers are encouraged to help families have a voice and to speak up for their children.

Adult Program for ASD: myLIFE-information from Connie Lillejord

- Anne Carlsen staff went to Emory Autism Center in Georgia.
- myLIFE program is for adults with ASD. Their philosophy is to support individuals in recognizing and preparing them for inclusive roles in their community.
- Social Engagement Groups:
 - Meet weekly and they participate in age-appropriate activities. Group members can practice skills in safe environment with staff and trained volunteers.
 - o They can use an apartment at Emory University to relax, cook and share leisure time.
- myLIFE groups:
 - o discoverLIFE and collegeLIFE-supports 18-24 years of age

- nightLIFE and liveLIFE-supports 25-35 years of age
- masterLIFE(semi-independent)- individuals who need minimal support or successful social connections with peers/personal skills or those who need one-on-one guidance/assistance with communication/safety skills
- The goals: Community and Family engagement:
 - Life enrichment: help members to stay fit, socially engaged and do volunteer activities
 - Life connections: connect with community resources/provide education
 - Life support: serve as a resource for parents and families. Help families learn key skills, also plan events where everyone comes together.
- Emory University also has volunteers- psychiatry residents who spend 4 sessions with the social engagement groups.
 - Anyone can volunteer

Connie also showed a short video clip regarding the program.

2019-2021 Biennial Budget

- DHS does not have budget guidelines from the Governor.
- At the face-to-face meeting in May, task force can provide recommendations/considerations for the 2019-2021 DHS budget.

Public Comments/information:

Free training in Autism Spectrum Disorder available through Vanderbilt. Please refer to handout 'free training in Autism Spectrum Disorders'.

Pathfinders need parents for their board. Pathfinders has a requirement that they have parents on their board.

Reminder for the 2018 meetings: May 14, August 20 and October 29 (all 1:00 p.m.-5:00 pm. CT)

Meeting Adjourned

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